



**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Health Resources and Services Administration**

**Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

**ACTION:** Notice.

**SUMMARY:** The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) has scheduled a public meeting. Information about the ACHDNC and the agenda for this meeting can be found on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** March 22, 2019, 10:00 a.m. - 3:00 p.m. ET.

**ADDRESSES:** This meeting will be held via webinar. While this meeting is open to the public, advance registration is required. Please visit the ACHDNC website for information on registration: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. The deadline for online registration is 5:00 p.m. ET on March 20, 2019. Instructions on how to access the meeting via webinar will be provided upon registration.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau (MCHB), HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or [AHarris@hrsa.gov](mailto:AHarris@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of HHS (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality

in newborns and children having, or at risk for, heritable disorders. ACHDNC's recommendations regarding inclusion of additional conditions for screening, following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA through the Recommended Uniform Screening Panel (RUSP) pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the March 2019 meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Tentative agenda topics include: 1) the condition nomination and evidence review process, 2) rare disease registries, and 3) implementation of conditions on the RUSP. Agenda items are subject to change as priorities dictate and the final meeting agenda will be available on ACHDNC's website:

<https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. Information about ACHDNC, a roster of members, as well as past meeting summaries are also available on the ACHDNC website.

Members of the public will have the opportunity to provide comments, which are part of the official committee record. To submit written comments or request time for an oral comment during the meeting, please register online by 12:00 p.m. ET on March 18, 2019. Visit the ACHDNC website for information on registration at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. Oral comments will be honored in the order they are requested and may be limited as time allows. Individuals associated with groups or who plan to

provide comments on similar topics may be asked to combine their comments and present them through a single representative. No audiovisual presentations are permitted. Written comments should identify the individual's name, address, email, telephone number, professional or organization affiliation, background or area of expertise (i.e., parent, family member, researcher, clinician, public health, etc.), and the topic/subject matter.

**John R. Womack,**

*Acting Deputy Director, Division of the Executive Secretariat.*

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